



Appendix H: Methodology and Validity of Public Health Data Sets

The race and classification scheme used in the U.S. was discussed in [Appendix B](#). That classification scheme, however, is only as good as its ability to be accurately applied by the people who report the data to the public health vital statistics and surveillance systems. In general, race and ethnicity are believed to be more valid to the extent that they have been self-reported. The following paragraphs describe the method used to classify an individual into one or more racial and ethnic groups. Known validity issues regarding the application of the race and ethnicity classification schemes in public health have been noted.

BIRTH CERTIFICATES

The child's mother and father complete a question sheet that includes all personal information, such as names, street address, race and ethnicity. The race and ethnicity fields are open-ended, meaning the mother and father write in words that describe their race and ethnicity. There is a standard coding system that classifies them according to what they wrote. The infant's race/ethnicity status is not derived from both the mother's and father's race and ethnicity; it is based only on the mother's.

DEATH CERTIFICATES

Race and ethnicity on the death certificate are completed by a funeral director. He or she speaks with the family of the deceased. The next of kin is usually considered the "informant" for purposes of completing the death certificate. Studies have shown that light brown-skinned races and ethnicities, such as Hispanic and American Indian/Alaska Native, are sometimes reported to be White and non-Hispanic. This appears to be a widespread problem affecting death data from most states. However, most decedents of non-White races are reported accurately.

COMMUNICABLE DISEASE SURVEILLANCE

The state requires mandatory reporting of all diagnosed cases of certain infectious diseases. Usually, a nurse from a local health department completes the disease report with the affected individual on the telephone and asks the person to self-report on separate race and ethnicity questions. However, the information is occasionally derived from medical records or physician reports.

HEALTH SURVEYS

Respondents to health surveys generally, although not always, self-report. The validity of the response is determined primarily by how well the race/ethnic categories used on the survey instrument match what the respondent thinks. The health surveys used in this report include the Behavioral Risk Factor Surveillance System (BRFSS), Pregnancy Risk Assessment Monitoring System, and the Utah Healthcare Access Survey (UHAS). BRFSS and UHAS include data only from Utahns with residential phones until 2009. For more information about state data sources, analysis techniques, and limitations, see <http://ibis.health.utah.gov/home/Help.html>.

UTAH CANCER REGISTRY

The Utah Cancer Registry derives cancer incidence records from several sources. The primary source is the hospital medical record. In most cases, the attending physician records the race and ethnicity information on the medical record, although it might also appear on the hospital admission form that was completed by the patient. Sometimes race and ethnicity information on cancer registry records derive from death certificates, in which case they would be prone to the same limitations as the death

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certificate data in general. Hispanic ethnicity for cases with missing data are derived from the New Mexico Spanish surname list.

UTAH BIRTH DEFECTS REGISTRY

Under Utah regulation, all hospitals and birthing centers are required to report any time a baby is born with a birth defect. Once the report is received, a staff member collects information from the medical records of the infant and the mother.

UTAH VIOLENT DEATH REPORTING SYSTEM

This surveillance system collects detailed information from death certificates, medical examiner records, police reports, crime lab records, and supplemental homicide reports on all violent deaths in Utah, including poisoning deaths, homicides, deaths of undetermined intent, unintentional firearm-related deaths, and deaths due to legal intervention.

UNITED STATES CENSUS BUREAU DATA

Population estimates and poverty rates derive from the U.S. Census Bureau. Until 2000, the U.S. Census Bureau collected demographic data once each decade, as part of the census count. Now, the Bureau continuously collects demographic information through the American Community Survey (ACS). The ACS is conducted by mail to persons with mailing addresses, with telephone and in-person follow-up, like the decennial census. The primary difference between the ACS and the decennial census is that the ACS uses sampling instead of seeking to interview all people. However, evidence suggests that sampling is better at estimating minority populations than census methodology.¹²⁸ The ACS interviews the resident population without regard to the person's legal status or citizenship. The survey is completed through random sample and undocumented residents are included. Anyone who lives in the United States for more than two months out of the year is usually considered a resident. "Non-citizen" includes any non-citizen, with or without a visa. Population estimates are generally very good, but do rely on response from individuals. Although no one is intentionally excluded from the survey based on citizenship status, and the information gleaned by the survey is not provided to immigration officials, questions remain about whether certain disenfranchised groups are willing to participate. See <http://www.census.gov/acs/www/Downloads/tp67.pdf> for more information.

OVERARCHING ISSUES

Hispanic persons who may be White by the Census Bureau definition will often report their race as "Other." The Hispanic ethnicity question is asked first on surveys to allow respondents to self-identify as Hispanic ethnicity prior to hearing the race question. But it appears that Hispanic persons often do not embrace the Census Bureau definition of race.

Classifying persons into standard race categories requires that the Census Bureau race definitions are known and understood. In South Asia (e.g., India), the Middle East, and the Philippines, classification errors are probably common.

Different data systems are adopting the Office of Management and Budget standards at different times.